

NEW JERSEY DEPARTMENT OF HEALTH AND SENIOR SERVICES
CENTER FOR HEALTH STATISTICS

STATEMENT OF POLICY ON RELEASE OF HEALTH DATA

This document is to be used in conjunction with the New Jersey Department of Health and Senior Services Statement of Policy on Release of Health Data, published March 1998.

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TABLE OF CONTENTS

Introduction	1
Information Available for Release	2
Data Files (Individual Level)	2
Reports	3
Review of Aggregated CHS-Generated Data	3
Attachment A: Agreement for Release of Public Use Data	4
Attachment B: Agreement for Release of Confidential and Sensitive Data	5
Attachment C: Standard Reports and Their Costs	6
Attachment D: Aggregated In-House Data	7

CENTER FOR HEALTH STATISTICS STATEMENT OF POLICY ON RELEASE OF HEALTH DATA

As part of the New Jersey State Department of Health and Senior Services (NJDHSS), the Center for Health Statistics (CHS) is responsible for collecting, maintaining, analyzing, and disseminating information found in a wide variety of data files. In turn, this information serves to address a host of topics related to health and health services.

In August, 1998, NJDHSS updated its general data release policy (in a document titled "New Jersey Department of Health and Senior Services Statement of Policy on Release of Health Data"). Under this policy, information on health facilities and other statistical summaries (e.g., tables of the frequencies of selected characteristics) can typically be made available under New Jersey's Public Record Statute N.J.S.A. 47:1A et seq ("Right to Know Law") with few restrictions, particularly if data have been aggregated or organized in such a fashion that specific individuals can not be identified. However, for those data files containing records referring to specific individuals, NJDHSS's general policy calls for appropriate reviews to protect confidentiality and privacy before any records are released.

This document describes the specific data release policies of CHS relating to those data files for which CHS has primary responsibility for the dissemination of information and the release of individual-level records. Like NJDHSS as a whole, CHS is also committed to promoting appropriate access to health data (i.e., as is stated in the NJDHSS policy "...as much health data as is possible within the restrictions of laws and regulations."). Reflecting its official role in disseminating health information on New Jersey, CHS is also dedicated to providing data of the highest quality at the lowest possible cost. Because many analyses of health-care issues are complex and multi-faceted, CHS is also supportive of collaborative "partnering" efforts (e.g., development of grant proposals and other mutually beneficial projects and publications) with properly qualified and responsible outside individuals or agencies to improve access to data and results.

Listed below are several general guidelines that CHS uses in dealing with the release of its data files. Beyond promoting affordable access to health data, these guidelines are also intended to afford protections for (a) confidential information such as individual identifiers and other data elements that might directly or indirectly associate specific persons with their records and (b) "sensitive" fields for which values may be error-prone or subject to misinterpretation.

1. As described in NJDHSS's data release policy, access to data fields containing confidential information requires the approval of NJDHSS's Institutional Review Board (IRB) for research purposes. In some instances, the IRB may be able to use an expedited review process.
2. Unless by an individual/agency with IRB approval or by an NJDHSS employee with the required official approvals to access confidential information, those receiving data from CHS must agree not to attempt to identify specific individuals who are the subjects of the records in a file.
3. Although there are some exceptions, any reports generated from data files of individual-level records released by CHS must adhere to the "Rule of 5" (i.e., cells with values less than 5 must be aggregated with other cells or not published at all). Noteworthy exceptions include the release of summary totals (e.g., statewide results) and the values in other cells that have already been released or published by CHS. In other instances it may be possible to publish cells with values less than 5, provided that the proposed publication is first submitted to CHS for advance review and comment, to be accomplished in no more than 30 days from receipt.

4. Except for cells that CHS has already released in its reports or in the form of statistical summaries, data on readily-identifiable, specific values of "sensitive" fields must not be released unless the proposed publication is first submitted to CHS for advance review and comment, to be accomplished in no more than 30 days from receipt. Designations of "sensitive" will be restricted to fields known to be error-prone (e.g., locations of events in small geographic areas) or in need of statistical controls or "risk adjustment" (e.g., specific hospitals to account for underlying differences in patient characteristics) to avoid common misinterpretations of results.
5. If any costs are required for the release of a data file, CHS will only charge for any (a) materials (i.e., the media on which the data are released), (b) labor (i.e., time to fulfill a given request), and (c) photocopies of necessary documents. These costs will be according to NJDHSS standard rates established at the time of a request.
6. NJDHSS reserves any copyrights to CHS data files.
7. Data files must not be re-released without CHS's written approval.
8. It is understood that some data files may not be in a finalized form (i.e., they may contain preliminary or provisional information) and, therefore, may be subject to change.

INFORMATION AVAILABLE FOR RELEASE

A. Data Files (Individual Level)

The data most often requested are statewide annual birth or death data. However, multi-year and partial-year birth and death data are also available as are some other data files (e.g., fetal deaths). The following procedures apply to any of these data sets.

1. Certain data items collected by CHS are confidential. These items could identify an individual. Other data items collected by CHS are sensitive. These items could cause erroneous conclusions to be drawn regarding certain minor civil divisions or facilities, for example, or in combination could identify individuals.
2. Public use files which omit confidential and sensitive data items are available. Anyone can request public use files and a release form must be signed.
3. Confidential and sensitive data are available only to internal users (within NJDHSS), other states' departments of health, and research organizations where the benefits of the research for the public good outweigh the risk of disclosure of confidential information. A completed request and a brief description of the proposed research must first be submitted to CHS. The proposal will then be reviewed by the Director of CHS.

If the request involves any confidential or sensitive data and if the director approves the brief proposal, a full proposal will then be reviewed by the Department's Institutional Review Board (IRB). [Note that any requests for confidential information from vital records also requires the approval of the Director of the Bureau of Vital Statistics.] For requestors within NJDHSS, an expedited IRB review may be performed through the Director of the Bureau of Vital Statistics. An approval from the IRB will require that a release form be signed by the requestor and a representative from the Department. A release form for confidential and sensitive data is contained in Attachment B.

B. Reports

1. Reports generated from the public use files and paid for by the user are considered public.
2. Certain standard reports will be available on a routine basis. Attachment C lists some reports that have been previously generated, along with their costs. Other reports may be created as needed.

All proposals and letters of request for fee-charged data should be sent or faxed (609-984-7633) to the following:

Director
Center for Health Statistics
Room 405
New Jersey Department of Health and Senior Services
PO Box 360
Trenton, New Jersey 08625-0360

C. Review of Aggregated CHS-Generated Data

1. CHS routinely collects aggregated data using CHS-generated forms and reports. These data are generally non-confidential in nature and, in accordance with the "Right to Know Law," may be inspected at the Department of Health and Senior Services. Individuals wishing to review or copy public information data from CHS-generated forms and reports are strongly encouraged to make an appointment with the appropriate CHS unit. Such requests will be reviewed by the unit's contact person. Appointments will be scheduled to allow the appropriate CHS unit ample time to prepare files for external review. All files will be reviewed in an area designated by the CHS unit to guarantee confidential treatment of all records. Requests from individuals appearing without an appointment may not be honored. At no time should outside reviews or copying of data interfere with a CHS unit's functioning. Failure to comply with these procedures will cause considerable delay in acquiring any information maintained by the CHS units.
2. Copying charges must be paid at the time of copying.

	The charges are:
First page to Tenth page	75 per page
Eleventh page to Twentieth page	50 per page
All pages over 20th	25 per page

Payment must be by check payable to "Treasurer, State of New Jersey."

3. A listing of CHS-generated data, which may be inspected at CHS, is found in Attachment D.

**NEW JERSEY DEPARTMENT OF HEALTH AND SENIOR SERVICES
CENTER FOR HEALTH STATISTICS**

**ATTACHMENT A
AGREEMENT FOR RELEASE OF PUBLIC USE DATA**

I am requesting the New Jersey data files listed below from the Center for Health Statistics (CHS).

I agree that these files will be in the custody of and maintained by _____ and will not be released to any other organizations or individuals without the prior written approval of CHS.

I further agree that no attempt will be made to identify specific individuals whose records are included in these files, or to link information from any other source to records for specific individuals. This includes adhering to the "Rule of 5," wherein cells showing reporting units of less than five (5) in number will be aggregated with other cells or not published. No listing of information from individual records will be published or otherwise released by the holder of these files. Measures will be taken to ensure physical and electronic security of records to properly protect individuals' confidentiality and privacy. I also agree to first submit to CHS for advance review any proposed publications of cells with values less than 5. It is understood that CHS must accomplish its review in no more than 30 days from receipt.

I agree to not copyright any results I may attain without the permission of the Department of Health and Senior Services.

I also agree to provide feedback to CHS regarding any errors in the data which I may encounter so that necessary quality improvement efforts can be undertaken.

I understand that any violation of the above conditions may result in prosecution under all relevant state and federal laws.

File/Description: _____

Requestor (print name): _____

Company/Agency: _____

Released to (print name, if other than Requestor): _____

Signature: _____

Date of Receipt: _____

CHS Representative (print name): _____

CHS Signature: _____

Date of Release: _____

**NEW JERSEY DEPARTMENT OF HEALTH AND SENIOR SERVICES
CENTER FOR HEALTH STATISTICS**

**ATTACHMENT B
AGREEMENT FOR RELEASE OF CONFIDENTIAL AND SENSITIVE DATA**

I agree to observe the following conditions of use of the New Jersey data files listed below which are being released to me and of information derived from these files:

1. The files will be used only to accomplish the research project as described in writing to CHS on (date) _____.
2. None of these files, or any files extracted or derived from them, will be released to any other organizations or individuals without CHS approval.
3. No attempt will be made to identify any specific individuals for whom records are included in these files.
4. No attempt will be made to link information from any other source to records for specific individuals for whom records are included in these files, unless expressed authorization is received from CHS. This provision, however, does not preclude statistical matches of individuals' records; i.e., those matches carried out by linking records for persons with similar characteristics, without attempting to ascertain that both records do, in fact, pertain to the same person.
5. _____ will be designated as custodian of these files and will be responsible for observance of all conditions of use and for establishment and maintenance of physical and electronic security arrangements to prevent unauthorized use. If the custodianship is transferred within the organization, CHS will be notified promptly. This individual must have the legal authority to keep the information confidential and maintain confidentiality.
6. No listing of information from individual records, with or without identifiers, will be published or otherwise released by the holder of these files. No statistical tabulations or research results will be released which reveal information about identifiable individuals. This includes adhering to the "Rule of 5," wherein cells showing reporting units of less than five (5) in number will be aggregated with other cells or not published.
7. Subject to conditions 2 and 6, statistical and research results derived from these files may be published. However, no results may be copyrighted without the permission of NJDHSS.
8. Feedback to CHS regarding any errors in the data which may be encountered will be provided so that necessary quality improvement efforts can be undertaken.

I understand that any violation of the above conditions may result in prosecution under all relevant state and federal laws.

File/Description: _____

Requestor (print name): _____

Company/Agency: _____

Released to (print name, if other than Requestor): _____

Signature: _____

Date of Receipt: _____

CHS Representative (print name): _____

CHS Signature: _____

Date of Release: _____

NEW JERSEY DEPARTMENT OF HEALTH AND SENIOR SERVICES

CENTER FOR HEALTH STATISTICS
ATTACHMENT C
STANDARD REPORTS AND THEIR COSTS

New Jersey Health Statistics

\$50 per year

An annual report of birth, death, fetal death, marriage, divorce, communicable disease, and population data and a subset of health objectives from *Healthy New Jersey 2000*. Data are provided for the state, all 21 counties, and some major municipalities. Report years available: 1989 - 1998. Published annually approximately 18 months after the end of the data year.

New Jersey Behavioral Risk Factor Surveillance System Summary Report Series

No charge

Pamphlet topics include:

Health Status of New Jersey Adults: 1991-1994 (published 1996)

Substance Abuse Among New Jersey Adults: 1991-1994 (published 1996)

Dietary Patterns and Physical Activity Among New Jersey Adults: 1991-1994 (published 1996)

Injury Prevention Practices Among New Jersey Adults: 1991-1995 (published 1997)

AIDS/HIV Awareness Among New Jersey Adults: 1991-1996 (published 1997)

Cancer Screening Practices Among New Jersey Adults: 1991-1996 (published 1998)

Routine Health Exams Among New Jersey Adults: 1991-1997 (published 1998)

Use of Clinical Preventive Services in New Jersey (2): Immunization and Hormone Replacement Status of Older Adults (published 2000)

Traumatic Brain Injury in New Jersey

\$15 per copy

A report on incidence of Traumatic Brain Injury morbidity and mortality in New Jersey. Report years available: 1994 and 1997. Published approximately three years after the end of the data year.

**DEPARTMENT OF HEALTH AND SENIOR SERVICES
CENTER FOR HEALTH STATISTICS**

**ATTACHMENT D
AGGREGATED CHS-GENERATED DATA**

Births: annual statistical reports dating back to 1879 (also available at NJ State Library)
additional municipality-level data for selected variables back to 1980

Deaths: annual statistical reports dating back to 1879 (also available at NJ State Library)
additional selected municipality-level data for selected variables back to 1977

Fetal Deaths: annual statistical reports dating back to 1916 (also available at NJ State Library)

Induced Terminations of Pregnancy:
annual statistical reports 1979-1988 (also available at NJ State Library)
selected cross-tabulations, 1989-1998

Marriages: annual statistical reports dating back to 1879 (also available at NJ State Library)

Divorces: annual statistical reports dating back to 1965 (also available at NJ State Library)

Population/Census:
NJDHSS employees: annual statistical reports dating back to 1896
municipality-level data for census years
Non-NJDHSS employees: contact the NJ Department of Labor at 609-292-0076